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The Public Health Response to HIV/AIDS: What Have We Learned?

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When trying to resolve a difficult situation in my current role as Director of the San Francisco Department of Public Health, I often ask myself: ‘How did we do it at the AIDS Office?’ The fact that seven years after leaving the AIDS Office to become Director of the Department, I still draw heavily on my six years in that office says a great deal about how AIDS energized and revolutionized public health.

Building San Francisco’s AIDS Program

San Francisco was hit early and hard by the AIDS epidemic. Along with New York City and Los Angeles, it was one of the first cities to diagnose AIDS cases, but

compared with these other cities, it experienced a much greater burden of disease because it had a markedly smaller population with a much higher concentration of gay and bisexual men. By 1983, a disease that had been unheard of just two years earlier had already affected 469 people in San Francisco and killed 182 of them. In a city of less than 750 000 inhabitants with a population of gay and bisexual men of approximately 58 000, AIDS had become the dominant issue.

Another major way in which San Francisco was different from other cities was the markedly greater political muscle of the gay community. In 1977 San Francisco became the first American city to elect an openly gay Supervisor/City Councilperson to office, Harvey Milk. When he was fatally shot, along with pro-gay Mayor George Moscone, in 1978, it further galvanized the gay community. A Milk supporter and an openly gay man, Harry Britt, was appointed by then Mayor Dianne Feinstein. He won re-election in 1979. Since that time San Francisco has always had at least one openly gay member on its Board of Supervisors; at times there have been as many as three gay and lesbian members of the 11 member body.

The political power of the gay community led to a very proactive approach towards AIDS by the San Francisco Health Department. The community recognized how serious a threat AIDS was, and clamored for the rapid development of services. At first the Department's response to AIDS was primarily through the Bureau of Disease Control, where the epidemiology staff tracked the epidemic. But as the need for services and prevention intervention efforts became paramount, the San Francisco Department of Health created the AIDS Office in 1983 with eight staff members. The Department decided to create a separate AIDS Office primarily because the rest of the Department could not move fast enough to handle the tremendous needs of this emerging infection. By the time I became Director of the Office in 1992, the Office had grown to about 90 staff members and had a budget of US\$43 million. When I left the Office in 1997, the budget was up to US\$73 million and over 100 people worked there.

Staff were initially drawn to work in the AIDS Office because they believed in the dual missions of the program: to care for HIV-infected people and to prevent others from becoming infected. The *esprit de corps* of the office was to work till the job was done, even if that meant 100-hour weeks. Being told that something could not be done in the county system was seen as a challenge and not as a deterrent; achieving the bureaucratically impossible task was a rite of passage for each staff member.

Beyond the work ethic, the Office developed several principles of how to do its job, in particular the importance of not making decisions in the traditional governmental way but rather establishing methods for participatory decision-making with and within the community. This has now become the dominant paradigm in the Department as a whole. For example, when we wanted to provide a more coordinated pre-hospital care system in San Francisco for residents calling 911, we convened a series of meetings in 1995 with Health Department paramedics, firefighters, private ambulance providers, union leaders, emergency room doctors and nurses,

and citizen representatives. For many of the participants, the philosophy of inclusiveness and the methods of consensus building that we had practiced regularly at the AIDS Office for several years, were new. Committee members were surprised at the willingness of the Department to let the process choose the new configuration for pre-hospital care, and even more delighted when they found they could reach consensus, despite several years of bickering, about the best way to configure services.

In addition to changing the decision-making paradigm, the AIDS epidemic broadened our view of the service continuum needed by clients. In fact, it was largely based on our success in providing supportive housing (i.e. housing with on-site supportive services such as case management, substance treatment) for people with AIDS, that our health department developed a supportive housing program for people with other medical illnesses. We have found that using a supportive housing model we have been able to take people suffering from mental illness, substance abuse, and other chronic illnesses (e.g. diabetes, chronic obstructive pulmonary disease) directly from the street and place them. Because this group has high medical costs when they are homeless, we have found supportive housing programs to be extremely cost effective: a month of housing costs less than a single day in our acute care hospital. The programs have also been able to retain two-thirds of clients in housing for two years or more.

The AIDS epidemic invigorated community mobilization and empowerment as prevention strategies. We have found these strategies helpful in a number of areas within the Department. For example, we have worked with elders and disabled people to develop ways of increasing pedestrian safety (i.e. bubble-out curbs at corners that shorten walking distances across intersections, lights that count down the time that people have to reach the sidewalk). Pushing the envelope further, our health department has mobilized injection drug users to learn how to give CPR and administer Narcan to shooting partners who overdose on heroin.

Many of the public health lessons have had national impacts on medical care for HIV/AIDS and other diseases. For example, the community mobilization around AIDS resulted in the Food and Drug Administration (FDA) speeding drug approvals for all types of drugs. The AIDS epidemic has also brought us a new type of advocacy, one that is not always polite, but often effective in influencing local and national politics.

These major changes in public health brought about by the AIDS epidemic are listed in Table 4.1 and discussed in greater detail below.

Decision-Making

The AIDS epidemic has had a major impact on how decisions are made within public health. Prior to the epidemic, the major paradigm in both public health and medicine was the 'expert/doctor' telling the 'patient/client/community member'

Table 4.1 Lessons from AIDS for public health.

Decision-making process	Share power with the community Involve affected people in all decision-making bodies Make certain that decision-making groups reflect the diversity of the problem Obtain and use data to make decisions
Service needs	Broad continuum of care including non-medical services and alternative medicine Case management for disenfranchised populations or people navigating complicated service delivery systems Need for cultural competency in all aspects of service delivery Importance of privacy
Disease prevention model	Limitations of traditional public health approach Importance of health education, health promotion, community mobilization, and community empowerment models
Advocacy	Affected people are the most effective advocates Single-issue advocacy works Advocacy does not have to be polite

what to do. This was not a paradigm that would have ever been successful in handling the AIDS epidemic.

The community first hit by AIDS was young gay men in urban areas. Having recently won greater acceptance on a societal level, gay men were not willing to accept, without questioning, the pronouncements of public health and medical leaders. Further, because AIDS was a new disease the public health and medical ‘experts’ really knew little more about it than members of the gay community, who were seeing first hand the devastation it caused. Some community-based non-professionals were rapidly developing their own theories, often closer to the truth than those of the scientific community, on the causes of AIDS.

Finally, because the prevention of HIV required community members to make behavioral changes voluntarily, the traditional public health approaches to handling epidemics – case finding, case treatment, vaccination, isolation – were not helpful. Instead, ways of engaging the community to support norms of safe sex were needed.

The AIDS epidemic has proven that the best way of gaining the support of a community is actively to involve them in the decision-making process. This requires ‘giving up’ power, something many government bureaucrats are loathed to do. But our experience has been that by giving up power, power is gained – the power to forge consensus solutions that marshal government and community forces behind the same mission.

The first step in shared decision-making is creating a panel of stakeholders. In the case of the AIDS epidemic, this meant individuals infected with the virus,

their friends and family, advocates, service providers, funders, and government officials. Key to the success of these panels is including substantial (rather than token) membership of the affected community. We strove to have at least a third of individuals serving on each committee to be people living with HIV/AIDS.

Because the AIDS epidemic represents several intertwining epidemics it was equally important to make sure that all groups were represented. The needs of white gay men were different from those of gay men of color, heterosexual drug users, women who contracted HIV from their sexual partners, transgendered individuals, and youth. All needed to be included.

Once constituted, the community panel must be given a clear charge (what is it you want them to do?) and a clear understanding of what will happen to their recommendations. Our experience has been that community groups can accept that their recommendations are advisory, or subject to veto by elected officials, as long as the process is made clear and is respected. Having the group elect a chair helps to empower the group members. Often having co-chairs from distinct constituencies (one from the affected community, one from government) helps to establish the principles of collaborative decision-making.

Once you have the right people around the table and they have been given a clear charge, you must provide them with the necessary data to make good decisions. In the absence of data people will argue based on their opinions and prior experience. Conversely, providing accurate data turns contentious meetings into productive, consensus-building dialogue. This is especially true when allocation of financial resources is at stake. We have devoted a lot of effort to providing our decision-making bodies with accurate data on the number of people living with HIV/AIDS, their service needs, and the number of people at risk for HIV and their risks for seroconversion.

Not that providing relevant data was easy. HIV was not a reportable disease in California until 2003 (although AIDS was). Confidentiality concerns precluded population-based sampling. Because of the long latency period between HIV seroconversion and development of AIDS, estimated at a median of 10 years, neither AIDS reporting nor HIV antibody tests were an effective means of determining where recent infections were occurring (Rutherford, 1990). Nonetheless, these challenges led to the development of creative surveillance models. Often in collaboration with the Centers for Disease Control and Prevention (CDC), we developed a variety of surveillance tools including phone surveys, clinic-based surveys, venue-based surveys, blinded seroprevalence studies, and, in more recent years, the sensitive/less sensitive 'detuned' ELISA, to provide detailed data on the epidemic. We also did specialized studies to focus on small, hidden populations that were never represented in sufficient number in countywide surveys. For example, we conducted surveys of young men who have sex with men (Valleroy *et al.*, 2000), transgendered individuals (Clements-Nolle *et al.*, 2001), and homeless youth (Gleghorn *et al.*, 1998). As Buehler has noted, the use of multiple surveillance methods to characterize the AIDS epidemic has informed efforts on how

to maintain surveillance for emerging infections as well as chronic diseases (Buehler, 2003).

The principles of community decision-making – shared power, inclusiveness, a clear charge, and a data driven process – have been interwoven into regulations concerning federal funding allocations. For example, the Health Services Resource Agency (HRSA), the funder of the Ryan White Comprehensive AIDS Resources Emergency (Care) Act of 1990, requires that each locality create a Council that includes consumers, service providers, and governmental officials, and other stakeholders to make decisions on allocation of resources to different service categories (i.e. the percentage of money going to medical care, the percentage going to housing, the percentage going to case management, etc.) (Marx, 1997). And, as testimony to the integrity of the process, allocations differ across localities and have changed over the course of the epidemic.

Similarly the CDC created a community-based planning process in 1994 to govern how federal prevention dollars are spent. The Prevention Planning Committee must include community representatives, epidemiologists, government officials, and other stakeholders. The groups are charged with identifying the best approaches for preventing infection among those groups at highest risk of becoming infected. To assure that each locality's request fulfills the priorities of its planning group, the CDC requires that the planning council issue a letter of concurrence (Valdiserri, 2003).

The San Francisco Department of Public Health has also found these principles of community engagement useful in a wide range of decision-making activities, including determining how to design a facility for people with chronic mental illness, how to decrease asthma incidence, and how to build a new hospital. We have noted that many funders, both governmental and private philanthropic groups, now require that programs create and support decision-making panels. This is a change that I expect will only increase in coming years as policy leaders recognize the value of community process.

Service Needs

As is the case for any serious disease, people with HIV/AIDS need medical services – doctors, nurses, hospital services, pharmaceuticals, and laboratory services. However, the AIDS epidemic has taught us the importance of providing a broader array of health-related services as shown in Table 4.2. Provision of supportive services was the central ingredient in what became known as the San Francisco AIDS Model. San Francisco's large, cohesive, gay community rallied to care for its own. A variety of supportive services were provided to help people with AIDS deal with the overwhelming issues of being diagnosed with a life-threatening illness. Services were provided by small, non-profit organizations working with a large cadre of volunteers (Arno, 1986).

Table 4.2 Health-related services needed for people with HIV/AIDS.

Traditional medical services	Physician visits Nursing visits Hospitalization Medications Laboratory
Alternative health services	Acupuncture Herbal remedies Megavitamins Massage
Supportive services	Benefits counseling/advocacy Housing Food Transportation Emotional support Legal services (e.g. wills) Day care Help taking care of pets
Related health services	Dentistry
Coordination	Case management

Investigators found that the San Francisco model was successful in shortening hospitalizations. Hospitalizations at the San Francisco General Hospital were significantly shorter (11.7 days) than hospitalizations for AIDS in New York (25.4 days) (Arno and Hughes, 1987). Based in large part on the success of the San Francisco model, the CARE Act provided funding to localities to provide a full continuum of services, including medical care, supportive services, alternative health services, dentistry, and case management (Marx, 1997). To recognize how radical a notion this was, remember that the federal Medicaid and Medicare programs do not pay for supportive services.

The Housing Opportunities for People with AIDS (HOPWA) program broadened the federal service continuum for people with AIDS to include housing. This appropriation from the US Department of Housing and Urban Development of US\$1.7 billion between 1992 and 2003 has provided funding for housing-related expenses (e.g. capital expenses associated with acquisition of property, rental subsidies, financial assistance to prevent evictions) (www.hud.gov/offices/cpd/aidshousing/programs/index.cfm). The program recognizes that many people living with HIV/AIDS are homeless or unstably housed and that it is extremely difficult to maintain health status and provide complicated medical treatments to people who lack stable housing.

The success of housing programs for HIV-infected people has led to greater support of housing as part of the service continuum for people with chronic disease,

including people with mental illness and substance abuse. Because studies have shown that localities can recoup 95 per cent of the costs of supportive housing (i.e. housing with supportive services) due to the decreased utilization of health services and lower incarceration rates (Culhane *et al.*, 2001), we are likely to see many more public health housing models in the coming years.

Early in the AIDS epidemic there were treatments for some of the opportunistic infections, but no effective treatments against the virus itself. Even when effective treatments became available (AZT was approved by the Food and Drug Administration in 1987) the treatments were highly toxic. It is therefore not surprising that many people with HIV/AIDS sought out alternative treatments. The most sought after alternative modalities have been acupuncture, herbal remedies, megavitamins, and massage.

What is especially interesting is how the use of alternative therapies by people with HIV/AIDS presaged the widespread use of alternative therapies by the general public. By 1997 42 per cent of Americans had used at least one alternative therapy in the prior year (Eisenberg, 1998). Not only has the use of alternative therapies become common in the general population, but these therapies have also been increasingly accepted and even encouraged by some Western trained physicians.

Providing coordination of care through case management has been found to decrease unmet needs for supportive services and also results in clients being more likely to receive life-saving treatment (Katz *et al.*, 2001). Based in part on the success of case management in helping people with HIV/AIDS to get the services they need, case management models have been developed for many other populations, including breast cancer patients, homeless people, and the mentally ill. Use of case management as a treatment strategy for disenfranchised people is likely to increase in the future.

Cultural Competency and Privacy

Because HIV/AIDS disproportionately affected stigmatized groups (e.g. gay men, injection drug users) and people of color, two other key principles of providing health care emerged from the AIDS epidemic: the importance of cultural competency of care providers and the importance of privacy.

The AIDS epidemic taught us the importance of understanding the cultural baggage that both providers of care and clients bring to the health encounter. For example, some people with HIV/AIDS have been reluctant to take antiretroviral therapy because of prior bad experiences with the medical system. Gay and lesbian people, drug users, people of color, and women all have reasons to be suspicious of the medical establishment given the prior practices and stated beliefs of medical professionals. Also, physicians may have preconceptions about certain types of patients (e.g. drug users will try to manipulate me to get unneeded pain medicines).

As the epidemic affected new populations, our understanding of culture needed to grow and deepen. For example, in the early 1990s a group of youth providers met with me to explain the importance of creating programs that were specific to youth. Until that moment I had never considered whether our programs were 'ageist,' i.e. whether youth would feel comfortable going to them. I just assumed that young people would choose what program to go to based on ethnicity, gender, sexual preference, and geography – the major ways that we had organized our services. I learned in discussion with youth – who expressed how uncomfortable they felt in adult-dominated clinical settings – that I was wrong; to make our system more culturally competent we devoted new resources to making our system competent for youth.

Cultural competency gives us a framework to understand and to deal with these issues. In San Francisco having a culturally competent AIDS system meant having ethnic-specific, sexual orientation-specific, and women-specific agencies, along with multicultural ones. It meant recognition that providing translators, although an important step, does not assure that people from different cultures are cared for in a competent way. Six years ago one rarely heard the term cultural competency outside of AIDS. Now several national bodies have created training manuals and advocated for cultural competency programs (Department of Health and Human Services, 2001; Linkins *et al.*, 2002). This movement is likely to increase because it is a better way of providing services.

Many people with HIV/AIDS fear disclosure of information about their health. This fear has been fueled by several cases of job discrimination, housing discrimination, domestic violence, as well as the inability of infected people to obtain life, disability, or health insurance (Institute of Medicine, 1986; Gostin and Webber, 1998). (Even having a *negative* HIV antibody test has at times been sufficient evidence for refusing coverage on the grounds that it suggests the person is in a high-risk group for HIV/AIDS.) Influenced by these lessons, as well as growing concern of the public about the increasing computerization of medical data, the Congress of the United States passed a national policy, the Health Insurance Portability and Accountability Act (HIPPA), with very strict rules governing release of medical information (Gostin, 2001).

Adapting the Disease Prevention Model

The traditional public health methods for controlling communicable diseases are case finding, case treatment, partner notification and treatment, quarantine, and vaccination. While these strategies have been helpful in eliminating and controlling a number of infectious diseases ranging from smallpox to gonorrhea, they have been much less useful in controlling the HIV epidemic.

As discussed above, HIV has a long asymptomatic latency period. Therefore, it has been difficult to identify people who are infected when they are still

asymptomatic. The only way to know for certain if a person is infected is for them to take an HIV antibody test. The test was first licensed in 1985, and it was initially unknown whether healthy people who tested positive for the antibodies would become ill or were immune (i.e. were like people who test positive for hepatitis B antibody and are immune to the disease). Unfortunately, natural history studies of HIV found that the vast majority of people who were infected would become ill if they did not receive treatment.

Even once the meaning of the test became clear, it has been difficult to convince at-risk asymptomatic people to have themselves HIV tested for a variety of reasons. The stigma attached to HIV results in HIV-infected people encountering discrimination in many areas of their lives including job discrimination, social avoidance, discrimination in receipt of medical care, and the impossibility of obtaining life, disability, or health insurance (Institute of Medicine, 1986; Kass *et al.*, 1992; Gostin and Webber, 1998; Herek *et al.*, 2002; Valdiserri, 2002). These all result in people at risk for HIV being reluctant to get themselves HIV tested. Also, psychological barriers such as fear and denial played a large role in people not going for testing or not returning for the results (Catania *et al.*, 1990; Irwin *et al.*, 1996).

The end result of all of these factors is that many people do not get themselves HIV tested until they have AIDS or HIV-related symptoms (Levi, 2002). Even once a person has tested HIV positive antibody there are still a large number of obstacles to successfully using a communicable disease control model. To prevent inadvertent disclosures of HIV status and to encourage at-risk people to test for HIV, the United States and other Western countries set up anonymous testing sites. Because testing is anonymous, it cannot be reported to health departments in the way that laboratories and clinicians report other communicable diseases. Therefore, any further action depends on the willingness of the client to disclose their result. Even assuming a client is willing to come forward, because no eradication therapy is available, case identification does not have the power it has with diseases such as syphilis or gonorrhoea.

Although partner notification has been used successfully with HIV in some populations (Landis *et al.*, 1992; Fenton and Peterman, 1997), a strategy that is very successful with controlling sexually transmitted diseases, is also hampered by the long latency period between HIV infection and development of AIDS (West and Stark, 1997). Especially among first time testers, it is unclear when the person became infected, making it extremely difficult to narrow down a likely set of sexual or needle-sharing partners who could then be interviewed. In San Francisco's gay community, where there is a high prevalence of infection, a high level of knowledge in the community about the likelihood that prior partners have been infected, and where many partners are anonymous, HIV partner notification has generally not been efficacious.

Quarantine, a very effective tool for infectious diseases with short latencies, such as severe acute respiratory syndrome (SARS), has no utility for HIV infection. It is neither practical nor ethical to quarantine people who are HIV infected, especially

since HIV can only be transmitted via intimate contact, prenatal exposure, or blood products, as opposed to diseases such as chickenpox and SARS that are transmitted through casual human interactions.

A vaccine – the ultimate weapon in the public health arsenal against infectious diseases, the vanquisher of smallpox, polio and measles – has proven elusive. In fact, since the HIV virus was first identified in 1984, scientists have predicted that an HIV vaccine with protective immunity is five years away. Sadly, it never seems to get any closer.

Because the traditional communicable disease control model has been of limited utility in combating HIV, the HIV epidemic has forced public health to rediscover and reinvigorate health education, community mobilization, community empowerment, and other public health strategies for controlling epidemics. Ironically, these strategies may be much more effective in battling the non-infectious disease epidemics that plague Western countries in the twenty-first century: obesity, diabetes, and substance abuse.

Health education and health promotion have been among the most effective weapons we have had in the battle against HIV. To protect themselves from becoming HIV infected people must know how HIV is transmitted and how to prevent it. Throughout the epidemic a variety of health education methods have been used to educate the public about HIV, including television and radio commercials, print ads in newspapers, bus shelters and billboards, group sessions in schools, churches, community centers, and individual sessions with doctors, nurses, health educators, and HIV antibody test counselors. Along the way, health education has successfully countered a number of misconceptions about HIV, including that you can tell by looking at a person whether they are HIV infected, that HIV can be transmitted through shaking hands or sharing bathrooms, and that you can't contract HIV from sex if you are straight (heterosexual).

Health education is and will continue to be a key strategy in communicating to the public about emerging infections such as anthrax and SARS. One of the frustrations with the federal handling of the 2001 anthrax outbreak in the United States was that the information provided by the CDC was not clear, accurate, and consistent regarding how anthrax was transmitted. In comparison, the handling of the SARS outbreak in 2003 was successful and the CDC was able to correct a lot of misinformation that was being spread about SARS.

Although necessary, knowledge is not in-and-of-itself sufficient to prevent HIV infections. For example, in San Francisco's gay community, where knowledge of HIV is high, HIV incidence rates remain high as well (Katz *et al.*, 2002). The reasons why people engage in unsafe sex even when they know that it could result in HIV infection range the whole spectrum of human motivations. People have unsafe sex because it is more intimate, it feels better, they are in a power relationship where they cannot demand that a condom be used, they are depressed, they are in denial that they can become infected, they are in denial that the other person is infected, they have such significant competing life problems that they are not particularly

worried that they will become infected, they are high on drugs, they believe it is inevitable that they will become infected, they believe that if they become infected they will simply take the necessary medications, the condom breaks, etc. (Penkower *et al.*, 1991; Stall *et al.*, 2003).

Although the reasons people put themselves at risk are large in number, we have learned through the AIDS epidemic a great deal about how to bring about long-lasting behavioral change. As exemplified by the response of San Francisco's gay community at the start of the epidemic, community mobilization is a very powerful health promotion strategy (Wohlfeiler, 1997). San Francisco's gay community was able to drive the new HIV infection rate down from a high of 8000 infections per year in 1983 to 5000 new infections by 1987 (Katz, 1997). What was especially remarkable about the success of this intervention is that it was done with relatively little government funding. While the government was stupefyingly slow in recognizing and funding prevention efforts (Francis, 1992), the community came together to prevent new infections (Shilts, 1987).

Starting in the early 1980s, the community made certain that no one would forget about AIDS. These activities are described in detail in Randy Shilts' book, *And the Band Played On* (1987). Informal discussions among friends and acquaintances expanded into community meetings with public officials, often heated. There were constant reminders of the need to stay safe from posters in windows of local stores and safe-sex brochures. Fundraisers were sponsored, and political work and lobbying efforts were carried out. Condom and Bleach man paraded through the streets at street fairs and festivals. (Interestingly, we have reused the concept recently to counter an increase in syphilis cases among men who have sex with men. We introduced the character the Healthy Penis along with his nemesis Phil the syphilis sore at the Gay Pride Parade to raise awareness of the growing number of cases.) The Sisters of Perpetual Indulgence (a group of men dressed in nuns' habits) dispensed safe-sex advice along with condoms. People volunteered to participate in studies like the San Francisco City Clinic Cohort and the San Francisco Men's Study so as to contribute to knowledge about HIV. The overall effect was development of a peer norm that emphasized the importance of each person protecting himself or herself against HIV.

The reason the community mobilization was so successful was that there was a clear threat to the community; the density of infection was high; the community was united in protecting itself; and it had social and political power (Katz, 1997).

Unfortunately, other communities that have been hard hit by the epidemic – injection drug users, communities of color – have not had the internal resources to mobilize. To overcome this limitation, we and other health departments have developed community empowerment models. The goal of an empowerment model is to spark the type of community mobilization that worked so well in the gay community. For example, several studies have shown that identifying, training, and supporting key community opinion leaders is successful in decreasing unsafe sex (Kelly *et al.*, 1991; Kegeles *et al.*, 1996; Valdiserri *et al.*, 2003).

Financially supporting empowerment models can be a bit of a challenge for government entities that are accustomed to tightly worded contracts that explicitly state what the 'deliverables' are. How can an agency state what services it will be providing if the point is to work with the community to determine what services they need? We handled this in the case of a gay/bisexual/queer and questioning youth empowerment model (Q action) (Wohlfeiler, 1997) by funding them to convene meetings of youth, ask the youth what type of program they wanted to do, and then use the money to implement the program. We never stated explicitly what the service was. (Getting this contract approved through our county bureaucracy was one of those 'rites of passage' accomplishments of the AIDS Office I spoke about in the introduction.)

Similar community empowerment models have been successful among low-income African American women (Sikkema *et al.*, 2000; Lauby *et al.*, 2000), among injection drug users (Rietmeijer *et al.*, 1996), and among diverse communities of high-risk people (CDC AIDS Community Demonstration Projects Research Group, 1999).

We, and others, have used community empowerment models to spark community interest in a number of non-AIDS areas over the last few years. For example, in response to the national epidemic of childhood obesity, our health department is currently working with a broad coalition to improve the nutrition of children. The coalition includes parents, youth, teachers, school officials, public health officials, physicians, nurses, and others. The coalition is taking a multipronged approach to improving nutrition, including health education, advocacy work with school officials on the importance of getting rid of junk food machines in the schools and providing instead healthful alternatives, and collaboration with local organic food producers.

Because the diseases that are of greatest risk to Western countries – cardiovascular disease, cancer – like AIDS, do not respond to traditional infectious disease control strategies it is likely that in the coming years there will be increased reliance on community empowerment models.

Advocacy

The AIDS epidemic produced the strongest single-issue advocacy that we have seen in the health field. Much has been learned from AIDS advocacy that is of use in the advocacy of people with other diseases. Because AIDS first hit highly stigmatized groups, the government was very slow to respond (Shilts, 1987; Francis, 1992). The result of this inattention was that the affected communities became much more politicized than they ever may have if the government had stepped in right from the beginning.

With only themselves to count on, the face of AIDS activism was not a professional lobbyist or advocate, but rather people with AIDS. Because they were dealing

with this devastating disease, people with AIDS had a validity that other spokespeople do not typically have. For example, in 1985 when Ryan White, a 12-year-old boy with hemophilia and AIDS was denied the right to go to school with other children his age, many people came to understand how profound prejudices were against infected people. And when the Congress appropriated the first emergency financial relief to localities caring for a disproportionate number of people with HIV/AIDS, it was named after him. This program provided almost US\$2 billion a year in 2002 for AIDS services in the United States (<http://hab.hrsa.gov/tools/progressreport/>).

The revelations that some famous people were suffering from HIV/AIDS, as was the case with Rock Hudson (announced in 1985) and Earwin 'Magic' Johnson (announced in 1991) – also had a tremendous impact on the general public. It is now widely recognized that the most effective spokesperson for any health issue – HIV/AIDS, breast cancer, substance abuse – is someone who is battling the illness.

Single-Issue Advocacy

However, the reasons HIV/AIDS activism has been successful go significantly beyond the effective use of patients as spokespersons. A second factor in the success of HIV/AIDS activism is the focus on HIV/AIDS as a single issue, rather than in the context of other health issues.

This may seem counter-intuitive. Why should focusing on HIV/AIDS exclusively, rather than using HIV/AIDS as an opportunity to highlight the broader problems with our health system be effective? The major reason is that it is much harder to provide the resources necessary to fix the health system, so that all people suffering from life-threatening diseases (AIDS in the era prior to the advent of effective antiretroviral therapy) or chronic diseases (AIDS in the era post development of effective therapy) receive the treatment they need. For example, the Ryan White (CARE) Act pays for a number of services – case management, substance abuse, transportation and housing – that people who suffer from diseases of equal severity are not able to access. Sometimes this produces ironic discrepancies in availability of care. For example, because of the success of HIV/AIDS advocacy in producing funding through the Ryan White CARE Act as well as local and state funding sources, I can arrange a residential substance treatment bed or a methadone maintenance slot within a day for one of my injection drug-using HIV-infected patients. However, for one of my uninfected injection drug-using patients, the wait for these services is several months. The irony of course is that substance treatment could potentially prevent the uninfected person from becoming infected. This discrepancy in funding availability has been referred to as 'AIDS exceptionalism' and has placed AIDS programs open to being attacked as unjust or unfair to other stigmatized populations with serious disease (e.g. mentally ill people) (Casarett and Lantos, 1998).

New Tactics

Another major reason for the success of HIV/AIDS activism is that it is not always polite. For example, many of the successes of HIV/AIDS activism can be attributed to the formation of ACT UP groups in several major cities in the United States and Europe. ACT UP stands for AIDS Coalition to Unleash Power and was formed in New York City in 1987 by activist Larry Kramer (Valdiserri, 2003). The civil disobedience tactics of these groups – closing bridges, sit-ins at governmental offices, booing speakers so that they could not be heard – while upsetting to some, unquestionably brought attention and results. This strategy was also made more successful by having other AIDS activists participate in advisory groups in more conventional ways. Agreeing to follow the recommendations of the more ‘moderate’ elements became a way of avoiding having to deal with the more extreme part of ACT UP. The effect of this ‘good cop/bad cop’ was seen in almost every facet of the struggle against AIDS. In fact, even the very definition of AIDS was heavily influenced by activism. Activists were rightly concerned that the surveillance definition used by the CDC was too narrow, with the result that many people were dying of AIDS without being counted. As a result, the 1992 expansion of the AIDS definition included three indicator diagnoses which were thought to be particularly common among disenfranchised people with HIV: recurrent bacterial pneumonia, pulmonary tuberculosis, and cervical cancer (CDC, 1992; Buehler, 2003).

HIV/AIDS activism had a tremendous effect on the federal drug approval process. Pressure by activists led the Public Health Service to approve an expanded-access program that made drugs available to affected individuals prior to the formal approval process by the Food and Drug Administration (FDA). The effort by activists also led the FDA to increase its speed in approving therapies. Both of these changes have benefited people with other diseases as well, including people with Alzheimer’s disease and cancer (Wachter, 1992). Equally significant, ACT UP pushed successfully for greater inclusion of women, ethnic minorities, and injection drug users in drug trials and other research on AIDS, an initiative now strongly supported by the National Institutes of Health.

ACT UP, along with other AIDS activists also helped change the methodology of drug studies. For example, AIDS advocates called for the acceptance of surrogate markers, such as improvements in CD4 lymphocyte counts as acceptable proof of the efficacy of drug therapy rather than requiring longer survival before approving drugs. Similarly, ACT UP and other advocates of people with HIV/AIDS pushed for the development and greater use of alternative research designs rather than randomized blinded controlled trials, such as open-label randomization (patients are randomized to therapy but know what they are taking). And when investigators failed to provide these types of studies, advocates taught research subjects how to get their medications tested outside of the study so they could learn whether they were receiving placebo or active medications. While these strategies were very

upsetting to investigators accustomed to performing their trials in traditional ways, researchers were spurred to develop new methods to deal with these real life situations.

What the Future Holds

Even if the AIDS/HIV epidemic ended, the lessons it has brought would continue to affect public health on a broad range of issues. The importance of community planning is well accepted among public health practitioners and is often an element required by federal and local funders. The benefits of providing a fully integrated continuum of services, beyond medical services, is equally well appreciated and is often requested by patients suffering from non-AIDS-related diseases, such as cancer and hepatitis C.

Prior to the AIDS epidemic one rarely heard about culturally competent care. If it was raised at all, it was usually in the context of caring for people who spoke a different language than the provider. But now we understand that language is only one part of cultural competency and health care institutions routinely assess themselves for cultural competency and seek to improve in those areas where they fall short. Part of the impetus for focusing on cultural competency is that it is a good business strategy (i.e. enables you to attract and keep customers) and it improves office morale and minimizes the risk for the employer of workplace harassment suits.

Passage of HIPPA has created new attention to the importance of maintaining privacy of medical information. The strength of community organization and empowerment models and the success of single-issue advocacy by people directly affected by a disease have been shown in the areas of breast and prostate cancer and hepatitis C. Overall, the greater involvement of affected individuals in their care can only improve outcomes.

What is less clear is how support for HIV/AIDS will change in the coming years. Is today's reduced community involvement an unavoidable result of prior successful community activism plus the discovery of effective drug treatment? Should it be a surprise that with patients living longer and better, the fear that motivated activists and ordinary individuals early on in the epidemic inevitably would wane? Perhaps the most telling (and disturbing) sign is how much less visible HIV/AIDS issues are in epicenters, such as San Francisco and New York. Agencies can no longer recruit as many volunteers; charitable giving to HIV/AIDS organizations is down; fewer people walk and run in organized fundraisers; several agencies have had to let go of staff or curtail their programs.

The indigenous community mobilizations around HIV/AIDS prevention in cities with large gay and bisexual male populations have fizzled out. In fact, multiple studies have shown significant increases in unsafe behavior as well as increases in sexually transmitted diseases in these cities (Kalichman *et al.*, 1997; Katz *et al.*, 1998, 2002; Van de Ven *et al.*, 1998; Ekstrand *et al.*, 1999; Dodds *et al.*, 2000).

And while experts debate whether ‘barebacking’ (anal intercourse without a condom) is a new phenomenon or a new spin on the small group of individuals who have consistently engaged in unsafe sex, the fact is that the peer norm in San Francisco and these other cities of consistently staying safe has dissipated.

Why has this occurred when there still is no cure or vaccine available? The reasons for the dissipation in community commitment to unsafe sex are numerous and complicated. But a very large part appears to be a product of our success: the availability of highly active antiretroviral therapy (HAART or ‘drug cocktails’) has had the result that people who once feared certain death if they were to become infected no longer have these worries (Chen *et al.*, 2002; Katz *et al.*, 2002). It turns out that fear of death was a very powerful spark of community mobilization.

Also, many of the behavioral changes that occurred in the early 1980s have been hard to sustain for the same reasons that many people who lose weight put it back on; the same reasons that many people who quit smoking relapse. As hard as it is to make behavioral changes it is even harder to sustain them for decades of time.

Whatever the causes, it is not surprising that as the gay community has shown less concern for preventing HIV transmission, that the general public is less interested in supporting these efforts as well.

The increased political strength of conservatives also bodes poorly for HIV/AIDS programs in the coming years in several ways. There has already been increasing pressure at the federal level to focus more resources on abstinence-only models and to not fund programs with extremely explicit materials. Although there is a place for encouraging abstinence, we know that it is not a strategy that is useful for the majority of people at risk for HIV.

We also know that for prevention programs to be maximally effective they have to appear relevant to the target audience. This is why it has been so disturbing that the federal government has ordered the San Francisco Stop AIDS agency to stop certain sexually explicit prevention workshops. Just a few months before the CDC had concluded that ‘the design and delivery of Stop AIDS prevention activities was based on current and accepted behavioral science theories in the area of health promotion’ (Ornstein, 2003). It was clear that conservative politics had triumphed over science. Similarly, HIV/AIDS and researchers in other areas of sexual behavior were chilled to find that their names had been compiled by a conservative group, the Traditional Values Coalition and submitted to Representative Billy Tauzin, a Louisiana Republican who chairs the House Energy and Commerce Committee. One of its subcommittees reviews grants awarded by the National Institutes of Health (Herbert, 2003).

There is also fear that HIV/AIDS programs will not fair well financially in the coming years. Already, several epicenters such as New York and San Francisco have had reductions in their total financial allocations under Ryan White (CARE) Title I. These losses have been difficult to sustain because while the incidence of AIDS (the annual number of new AIDS cases) has dropped dramatically, the number of people living with AIDS has dramatically increased. The reason is that HAART

has resulted in fewer people developing AIDS but has resulted in an even greater reduction in the number of AIDS deaths.

In addition to the increase in the size of the population of people with HIV/AIDS, the costs of providing pharmaceutical care to this group continues to increase. To date, most of the costs of AIDS drugs have been covered via a combination of federal and state funding through the Medicaid program and the AIDS Drug Assistance Program (ADAP). ADAP is funded through the Ryan White Care Act. In 2003, the funding for ADAP (federal and state) was US\$948 million (<http://www.hab.hrsa.gov/programs/factsheets/adap1.htm>), up from US\$204 million in 1996, the year that protease inhibitors first became available. In addition to these increases in funding, several cost-savings methods have been applied including use of a variety of pharmaceutical discount programs. Unfortunately, despite these increases in funding and cost savings measures, ADAP funding is insufficient to cover demand for medications. The result is that many states in the United States effectively ration medications to economically poor, uninsured people with HIV/AIDS by maintaining wait lists, limiting the total number of drugs a person with HIV/AIDS can receive, or restricting the formulary (not including all effective drugs on the formulary). As these restrictions increase, we could see a greater and greater disparity by income in the percentage of HIV-infected people receiving treatment and decreased survival among low-income populations due to them being less likely to receive treatment (McFarland *et al.*, 2003).

I fear that in the next years AIDS exceptionalism will end, but not the way I had hoped. My hope has been that we would resolve the dilemma caused by AIDS exceptionalism by providing the same needed services for all people suffering from illness. For example, if the United States provided universal health insurance with drug coverage it would not be necessary to fund the medical care components of the Ryan White (CARE) program or the ADAP program. Instead all people with serious illness would have access to needed medications. Similarly, were the same support services available for disenfranchised populations or those who have to navigate a difficult treatment system, we would not need services only for people with HIV/AIDS. Instead I fear we will see AIDS exceptionalism end by no longer providing needed medical care or supportive services to people with HIV/AIDS or any of the populations struggling with poverty and serious illness.

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